

MEMORANDUM

DATE: October 31, 2007

TO: Mr. Joseph B. Keyes, Ph.D.
Applicant Services Unit
Division of Developmental Disabilities Services

FROM: Daniese McMullin-Powell, Chairperson
State Council for Persons with Disabilities

RE: 11 DE Reg. 423 [Proposed Eligibility Regulation]

The State Council for Persons with Disabilities (SCPD) has reviewed the Department of Health and Social Services/Division of Developmental Disabilities Services' (DDDS) proposal to amend its regulations regarding eligibility criteria related to DDDS services. The regulation was published as 11 DE Reg. 423 in the October 1, 2007 issue of the Register of Regulations. As background, SCPD previously commented on an earlier version of these proposed regulations which were published at 11 DE Reg. 18 (July 1, 2007). Please see attached July 13, 2007 letter. DDDS has now issued a revised set of proposed standards. The revised version remains substantively problematic. SCPD has the following observations and recommendations.

First, the preface to the regulation (at 423) and public notice (p. 523) recite that the Division will convene a public hearing to receive comments. However, no time and date of the public hearing are provided. This violates the APA which provides as follows:

The notice shall state the manner in which persons may present their views: (i) if in writing, of the place to which and the final date by which such views may be submitted; or (ii) if at a public hearing, the date, time and place of the hearing. If a public hearing is to be held, such public hearing shall not be scheduled less than 20 days following publication of notice of the proposal in the Register of Regulations.

Title 29 Del.C. §10115(a)(2). [emphasis supplied]

Second, in Section 1.0, DDDS should substitute “meet” for “meets” for ensure proper grammar.

Third, as noted in the Council’s July comments, the regulation is inconsistent in its use of the terms

“disability” and “disorder”. The reference in the overriding standard (§1.0) is solely to “disability”. Likewise, §1.5 solely refers to disability. In contrast, §1.3 refers to both “disability/disorder” and §§ 1.3.3 and 2.0 solely refer to disorder. The term “disorder” is ostensibly a broader term than disability. For consistency, the Division should consider amending §1.0 to refer to “disability/disorder”, i.e., the same language used in §1.3.

Fourth, there is some “tension” between §1.1 and the recent decision in Duffy v. Meconi, No. 05-127 (D.Del. September 11, 2007). At a minimum, SCPD recommends consideration of the following amendment:

...a resident of the State of Delaware; provided, however, that the Division may entertain, assess, and process an application from a non-resident who confirms the intent to establish Delaware residency; ...

Otherwise, the regulation would literally preclude the Division from providing the assessment services necessary to determine eligibility.

Fifth, as noted in SCPDs July comments, the word “generalized” should be deleted from §§1.3.1 and 1.3.5. The Council’s remarks remain apt:

References to “generalized limitation in intellectual functioning” are anachronisms. They were present in the 1983 AAMR definition. See AAMR, *Mental Retardation: Definitions, Classification, and Systems of Supports*, 10th Edition (2002) at p. 22. The 2002 AAMR criteria affirmatively reject the notion that limitations must be “generalized”. Rather, they recite that “within an individual, limitations often coexist with strengths.” At pp. 8 and 23.

Sixth, as noted in the Council’s July comments, the format of the regulation is awkward. For example, there is no punctuation whatsoever at the end of §1.1, 1.2, 1.3.4, 1.3.5, 1.4, and 1.5. It resembles a conceptual draft rather than a formal regulation.

Seventh, the new “grandfather” provision (§1.6) is problematic. For example, consider a current client who qualified under 1999 DMR criteria based on having functional limitations in both social skills and functional academics. The 1999 DMR standards required functional limitations in 2 adaptive skill areas:

“Mental retardation” refers to substantial limitations in present functioning. It is characterized by significantly subaverage intellectual functioning, existing concurrently with related limitations in two or more of the following applicable adaptive skill areas: communication, self-care; home living; social skills, community use, self-direction; health and safety; functional academics; leisure; and work. Mental retardation manifests before age 18.

If that client no longer has functional limitations in functional academics, he/she would no longer meet the “requirements of the regulation under which the client initially established eligibility”. The Catch-22 is that the client is categorically precluded from invoking eligibility under the new regulation since, literally, “the requirements of 1.3 through 1.5 shall not apply to any client who is

receiving services on the effective date of these regulations”.

The same Catch-22 would apply to a current DDDS client with Asperger’s Disorder. If DDDS has some clients with Asperger’s Disorder whose overall skills have improved somewhat with age, they may not meet the eligibility standards from years ago and they are categorically precluded under §1.6 from establishing eligibility under the new standards.

The Division should abandon this concept of subjecting all current clients to maintaining eligibility under standards which applied when initially determined eligible. Query whether the Division even has the criteria from the 1930s and 1940s to apply the regulation to older clients. There were Stockley Center residents and former Stockley Center residents admitted to DDDS-predecessor agency services under archaic and discredited “eligibility” criteria based on the Eugenics movement. Query whether current clients should be subjected to an assessment of whether they currently qualify as an idiot, imbecile, or moron?

Eighth, the Division has reinstated a limited authorization for persons with brain injury or neurological conditions related to mental retardation to qualify for DDDS services. Section 1.3.5 recites as follows:

Brain injury or neurological condition related to mental retardation that meets: a) a significant generalized impairment in intellectual functioning (defined in 1.3.1); b) significant limitations in adaptive behavior functioning (defined in 1.4); and c) originates before age 22 (defined in 1.5).

A. At a minimum, the structure of this standard should be reassessed. Pars. b) and c) are completely redundant. Everyone qualifying for DDDS services must meet the standards in §§1.4 and 1.5. There is no reason to repeat the adaptive functioning and age-22 onset standards. Consistent with the “Sixth” comment above, DDDS should insert “; and” at the end of §1.3.5 to clarify the Division’s intent. This would result in the following:

1.3.5 Brain injury or neurological condition related to mental retardation which meets the criteria of intellectual functional limitation contained in §1.3; and

B. While the reinstatement of limited eligibility for persons with brain injury in §1.3.5 is welcome, it remains narrowly defined to only include persons with both intellectual functioning in the mental retardation range and adaptive functioning limitations. Since DDDS is not requiring low intellectual functioning for persons with Asperger’s Disorder, Autism, or Prader-Willi Syndrome, it is anomalous to impose the requirement on persons with brain injury. Consistent with the Council’s earlier commentary, SCPD still strongly recommends the following substitute for the proposed §1.3.5:

1.3.5. Brain injury, including Dementia Due to Head Trauma (294.1)(American Psychiatric Association Diagnostic & Statistical Manual-IV, 1994); and/or

Applicants with brain injury would still have to meet the same adaptive behavior limitations applied to other conditions through §1.4.

If DDDS is disinclined to adopt this recommendation, a less desirable option would be the following compromise:

1.3.5. Brain injury characterized by limitation in intellectual functioning defined as IQ scores approximately one standard deviation below the mean.

Consistent with the attached I.Q. table, this would equate to an I.Q. of 85. Alternatively, DDDS could consider adopting a standard of 1.5 deviations below the mean which would equate to an I.Q. of approximately 77.5.

C. Substantively, the regulation is highly objectionable since it does not “capture” conditions “similar to Autism, Asperger’s Disorder, and Prader-Willi Syndrome”. See attached July 13, 2007 SCPD comments, at p. 3. There are both rare and common conditions which may be categorically excluded from DDDS eligibility by barring eligibility of persons with similarly impairing diagnoses. For example, individuals with hyperphagic short stature (HSS) have very similar profiles to individuals with Prader-Willi Syndrome. See attached comprehensive study. Insatiable eating (hyperphagia) is similar for both diagnoses. Children with HSS had a mean I.Q. of 77 while children with PWS had a mean I.Q. of 54 with the highest I.Q. being 90. If an application were filed with DDDS for an individual with Prader Willi Syndrome with an I.Q. between 70-90, that individual would not be disqualified. The same individual with an HSS diagnosis would be categorically disqualified. This is not a “fair” or desirable result. Consistent with the Council’s prior commentary, the following should be substituted:

1.3.6. A neurological disability/disorder closely related to those listed in §§1.3.1 to 1.3.4; including Pervasive Developmental Disorder (American Psychiatric Association, Diagnostic & Statistical Manual-IV, 1994); if such disorder results in an impairment of intellectual functioning and/or adaptive behavior functioning similar to such disorders.

Thank you for your consideration and please contact SCPD if you have any questions or comments regarding our observations or recommendations on the proposed regulation.

cc: Ms. Marianne Smith
Ms. Susan Cycyk
The Arc of Delaware
United Cerebral Palsy
Autism Society
Brain Injury Association
Governor’s Advisory Council for Exceptional Citizens
Developmental Disabilities Council